



healthwatch York

CAMHS Review 2017

A report based on local peoples' experience

August 2017

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CAMHS Review 2017

Introduction

This report presents parents' experiences of Children & Adolescent Mental Health Services in York.

What is CAMHS?

CAMHS stands for Child and Adolescent Mental Health Services. CAMHS is a service for children and young people under the age of 18 with emotional, behavioural or mental health difficulties. They can support young people experiencing a range of problems such as depression, problems with food, self-harm, abuse, violence or anger, bipolar, schizophrenia and anxiety.

There are CAMHS services all around the UK. There are both outpatient and inpatient services in York; the outpatient service is called Lime Trees, which is provided by Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV), commissioned by NHS Vale of York Clinical Commissioning Group (VoYCCG). The inpatient service – Mill Lodge, is provided by Leeds and York Partnership NHS Foundation Trust, commissioned by NHS England. It is not a local facility, and treats children and young people across the region and nationally.

How does a child or young person get help from CAMHS?

Usually, a child or young person is referred for an assessment with CAMHS by a parent, teacher, or GP, or self-referral if they are old enough.¹ The assessment allows a specialist to understand the problems the individual is facing, and how CAMHS may be able to support them.

Each locality can be different. In York, the referral process involves an initial assessment with a primary mental health worker. They may then refer the individual on to be seen by somebody from the CAMHS Lime Trees service.

¹ Referral is via Single Point of Access (SPA) has been in place since Oct 2016. Self-referral has been in place since July 2017 for parents/carers and adolescents.

Why is Healthwatch York looking at CAMHS?

In December 2016, York Carers Centre contacted us. They told us about the issues parent carers were raising about CAMHS services in York. We met with York Inspirational Kids in June 2017. They also highlighted the difficulties parents were facing getting support from CAMHS, and also raised concerns surrounding funding for mental health services in York.

We have also been contacted directly by individuals sharing their views on CAMHS services.

National and Local Picture

Nationally, there has been an increase in focus on children and young people's mental health over the past 20 years or so. This has been particularly following the Children's Act 2004, which put forward the aim to improve children and young people's outcomes, including their health and wellbeing.

The Five Year Forward View for Mental Health, published in February 2016, has a specific focus on children and young people's mental health. In the Health Education England Report published in August 2017, the NHS set out plans to recruit more staff for CAMHS, and to increase the number of children and young people with diagnosable mental health conditions receiving treatment from community mental health services from 28% in 2016/17 to at least 35% by 2020/21. It must be noted that this is based on a prediction in 2004 of the number of individuals that would be experiencing mental ill-health today. However, the current number of those accessing mental health services would suggest that rates are increasing, meaning funding is not in line with the increased demand for services.

The Vale of York CCG developed a Local Transformation Plan (LTP) to meet the national ambition for mental health for children and young people following the Future in Mind report by the Department of Health and Department of Education in 2015. This LTP sets out the plan for transforming children and young people's emotional and mental health in our local area.

There are 5 local priorities:

- Community Eating Disorder Services
- Development of 'Children and Young People's IAPT principles'
- Promotion, prevention and early intervention
- Easier access to support
- Support for the most vulnerable

The actions set out in the LTP include:

- Named emotional and mental health lead in schools, working alongside the CAMHS worker, Healthy Child Programme, pastoral team, Emotional Literacy Support Assistants and Special Educational Needs Co-ordinators
- Single Point of Access (SPA) into CAMHS
- Online tools and access to help and advice children and young people
- Supporting vulnerable children and their families within the school environment
- 'Working Better Together' as a theme across agencies and organisations, including:
 - Mapping pathways across agencies to ensure clarity, consistency of approach and effective communications'
 - The outcomes of this will be that:
 - Services work and communicate better together
 - Patients and families understand the options for advice, care and support
 - Children and young people are directed to the most appropriate services for their needs
 - The principles of joint working across agencies are reinforced and developed²

An update in September 2017³ outlined how they had already launched a City of York school well-being service. This means every 'school cluster' has a dedicated well-being worker who can advise and support staff, and provide direct support to individuals and groups of pupils. The purpose of this service is to improve early intervention. A similar scheme has been set up in the North Yorkshire County Council area also. The Single Point of Access (SPA) is now operational, as is the extended crisis response. There are also national targets and performance

² Vale of York Clinical Commissioning Group in their Transformation Plan for Children and Young People's Emotional and Mental health 2015-2020

³ Future in Mind Local Transformation Plan (LTP) refresh 2017

indicators for Children and Young People's Mental Health Services, which include levels of access to services, and waiting times for certain services such as eating disorder services and psychosis services.

The LTP is updated annually, and the aims for the 2017/18 update include:

- Increasing the awareness of and availability of early support
- Reducing waiting times further

Recently, Child and Adolescent Mental Health Services in York have been discussed in the political arena. York Outer MP, Julian Sturdy, took the issue of waiting times in the York area to Parliament in February 2017.

Current state of CAMHS in York:

The Vale of York CCG target for assessment times is that 90% of people who have been referred for an assessment should be assessed within 9 weeks of referral. However, between September 2016 and April 2017, the average was 66%.

According to NHS Vale of York Clinical Commissioning Group Quality and Patient Experience Report (July 2017), of those waiting for an assessment or treatment with CAMHS in York, 22% of people are waiting longer than 12 weeks for an assessment. Of those who are then referred on for treatment, 72% are waiting longer than 12 weeks to start the treatment.⁴

The Mental health performance update at the September 2017 Vale of York CCG Governing Body Meeting presented the issues surrounding CAMHS services in York. They identified the problem as 'potentially poor quality service for patients as a consequence of long waits for patients to be assessed potentially leading to delays in active treatment'. They detailed the actions that had been put in place by TEWV in response to this, which included streamlining pathways; investing an additional £380k into the service; introduction of the Single Point of Access service. Some funding from NHS England was used to address some of the pressures on the waiting list, which alleviated local pressures for a time.

⁴ From 'NHS Vale of York Clinical Commissioning Group Quality and Patient Experience Report – July 2017' and 'Programme Overview – Mental Health, Learning Disability, Complex Care and Children – Validated data to April 2017'

The York and North Yorkshire Children and Young People's Community Eating Disorder Service has also been established, launching on 1 April 2016. A crisis liaison service has also been developed, with an extension of their opening hours from 1pm to 9pm to 10am to 10pm seven days a week from September 2017.

A Single Point of Access (SPA) for CAMHS in York, is where 'all new referrals come through SPA and will receive at least 30 minute phone call with a clinician on duty, who will decide on the appropriateness of a full assessment or signposting to other services'. Initial feedback following its introduction in 2017 include that 'staff report that SPA has been well used, with the effect that a more consistent service is developing across the area as staff develop a common approach towards referrals handling'⁵.

However, the York Carers Centre have highlighted to us that since the introduction of the SPA for CAMHS, some parents have reported that things have improved, whilst others have said they have not. One concern is that some individuals trying to access services prior to the introduction of the SPA could still be waiting for support or treatment from CAMHS.

York Carers Centre raised the issues they were seeing with CAMHS to TEWV. As a result of this, they were offered:

- A meeting with Ruth Hill Director of Operations & Carol Redmond CAMHS lead
- Opportunity to attend a staff meeting & explain about York Carers Centre services. This was well received and staff at TEWV seemed keen to know as much as possible
- Information about the new Single Point of Access
- Support for Young Carer Lead in working through issues with young carers needing MH support
- The Young Carers Lead was also invited to be a part of the 'CAMHS Executive Strategy group' (now known as the 'Strategic Partnership – Emotional and Mental Health Meeting')

The lead officer for adult carers at the Centre, and the young carer lead attended the meeting as above and raised a number of issues. They told us that they felt reassured that the new SPA would help to alleviate some of the things they were hearing from families. They also provided

⁵ NHS Vale of York CCG – Quarter 4 Progress Report Future in Mind Transformation Plan

TEWV with an example of a young person who had been let down; TEWV said they would follow up on this situation, and they welcomed other examples in order to inform development and training.

What we did to find out more

We agreed that a survey into CAMHS services would be helpful to understand parents' experiences of these services in York. York Inspirational Kids kindly offered to launch a survey reviewing parents' experiences, and this ran for approximately two weeks in June and July 2017. This gave people a very short response time, providing us with a snapshot of people's current experiences.

There were 55 responses to the survey in total. We appreciate this is a small sample of those using CAMHS, but it provides meaningful insight into how they hope services can change.

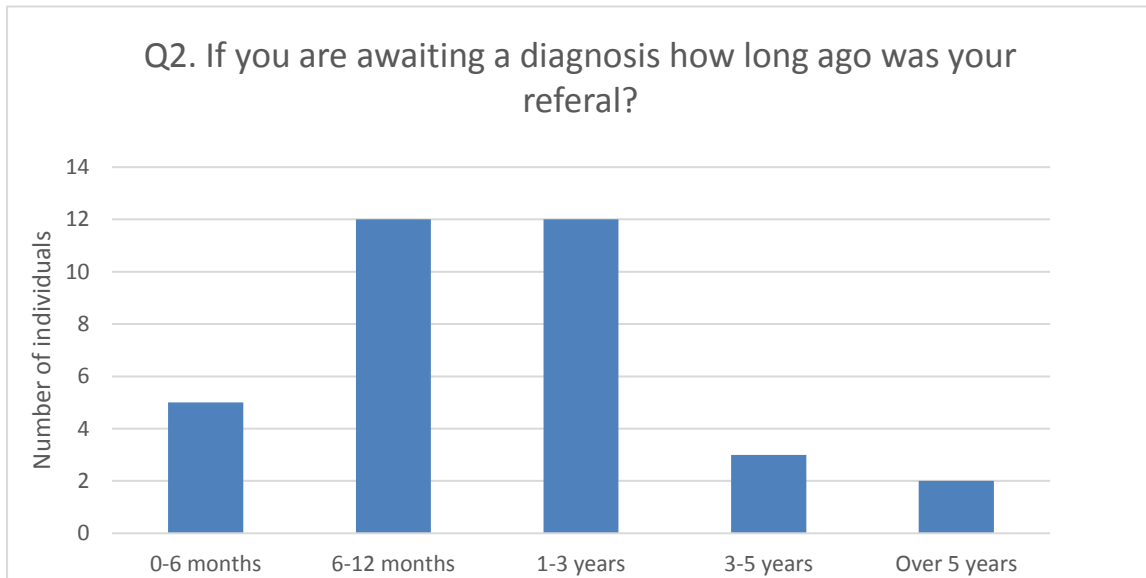
We also looked through our issues log and any direct contact from parents/carers we have previously regarding CAMHS services, and took into account the information we had received from York Carers Centre alongside our survey findings.

What we found out

Question 1: How old is your child that is accessing/awaiting access to CAMHS?

Age	
0-5 years	2
5-11 years	26
11-16 years	26
16 years +	1

Question 2: If you are awaiting a diagnosis how long ago was your referral?



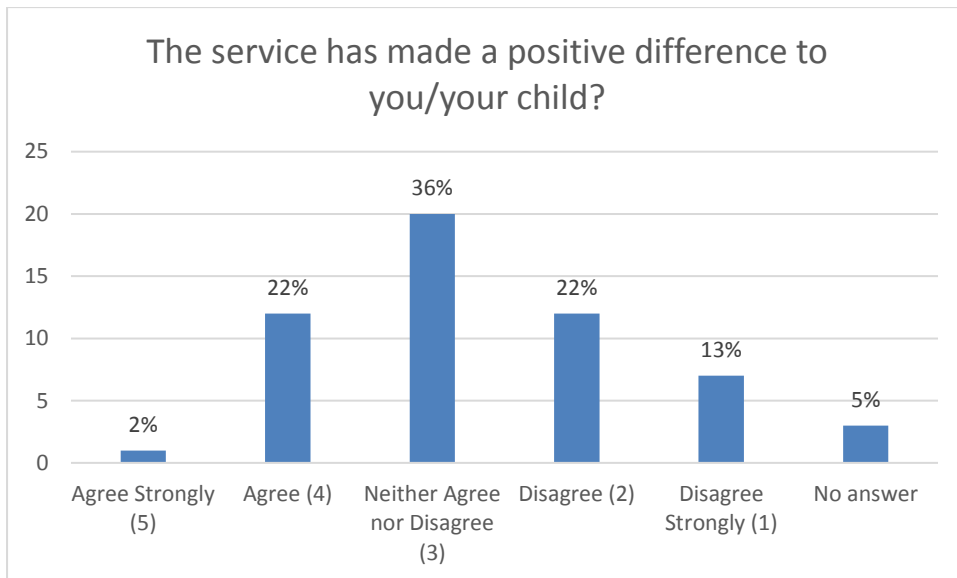
34 responses in total

Question 3 asked parents whether they agreed with certain statements about CAMHS.

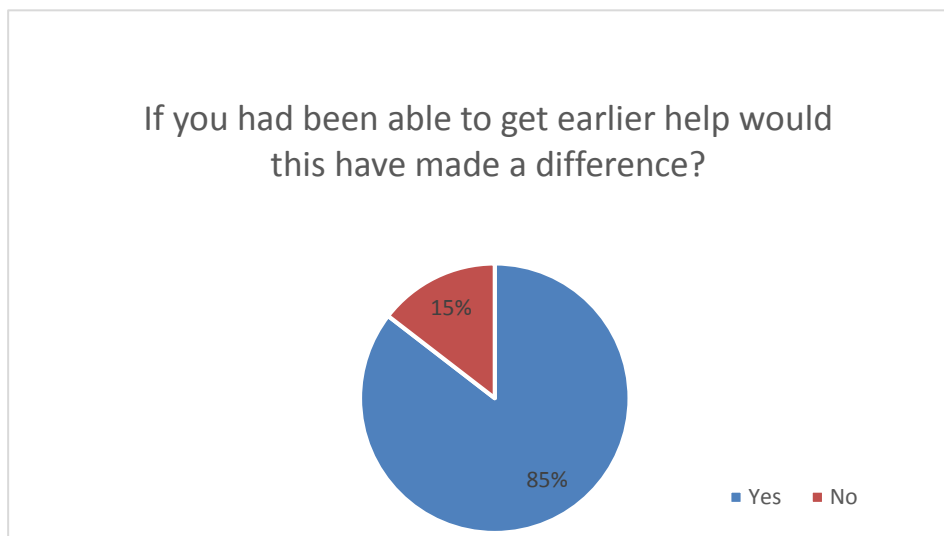
The statements and their responses were:

- 36% said that the people who are working with their child are easy to talk to
- 27% of people said they felt that their views as a parent are listened to by CAMHS
- 22% agreed that CAMHS understand their child's needs
- 11% said they have been given advice about where else they might be able to get help
- 9% agreed that they feel that people at CAMHS know how to help their child
- 5% agreed that the length of time support is available is good (e.g. weeks, months or years)
- 4% agreed with the statement: 'I have been given enough support to help my child'
- Nobody said that it was easy to get an appointment

Question 4: Has the service made a positive difference to you/your child?



Question 5: If you had been able to get earlier help would this have made a difference?



85% of people answered yes.
15% of people answered no.

Question 6 asked: if you answered yes above, please explain why.
Themes from the answers included:

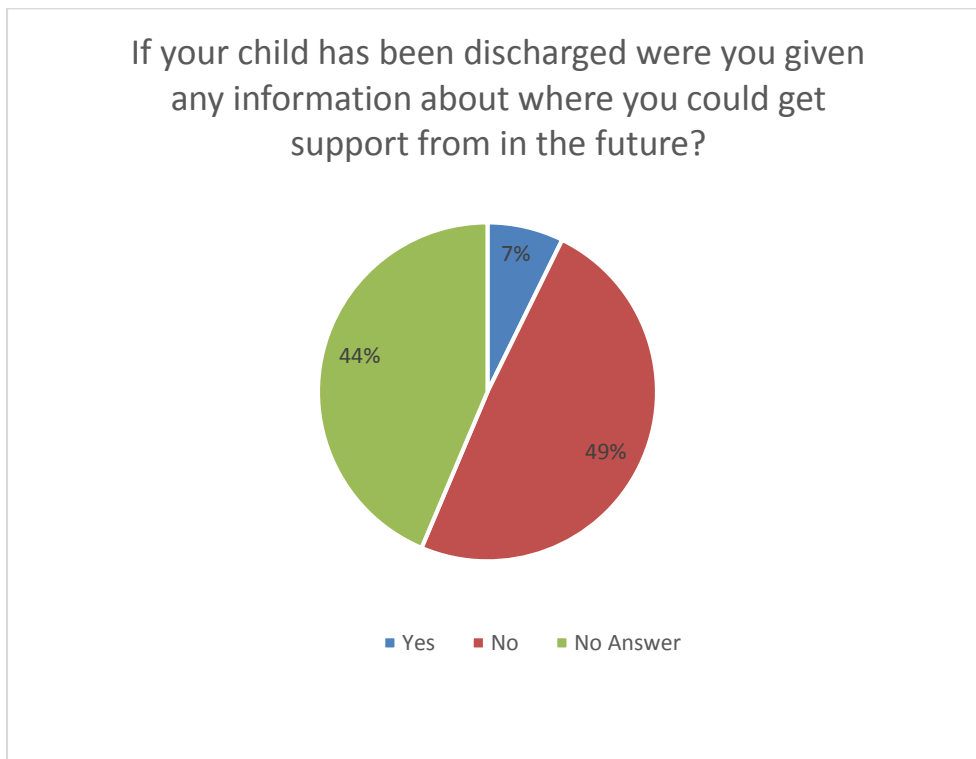
- Lack of diagnosis meaning lack of support or understanding of how best to deal with the problems/issues
- Prevention of difficulties at school – having a diagnosis/support, would have meant better support and knowledge of how to help
- Long wait for contact/support/diagnosis meant increased anxiety
- Earlier help may have prevented the child's mental health deteriorating
- Pressures on family to try and deal with the problems without knowledge of how to best support the child

Comments included:

- 'Earlier help would have helped increase support at school'
- 'Knowing what the condition is would help in understanding how to deal with it appropriately'
- 'If earlier diagnosis had happened, support from other agencies and school would have been put in place when really needed. Instead my child's needs increased through anxiety of school not knowing what to do, no support for us as a family and we hit crisis point before getting screening and diagnosis'
- 'It would have stopped the prolonged anxiety that both my children experience'
- 'It might have stopped things from reaching crisis point'
- 'Would have avoided stress and breakdown of relationships in family'
- 'There would have been more help earlier and strategies in place so he was able to do well instead he was slipping further away from his education and lost confidence'
- 'Early intervention would have helped manage anxieties with both my son and rest of family but due to the long waiting times and having to keep re-referring through school/GP the difficulties have...resulted in crisis for whole family'
- 'We didn't know what to do for him, how to help him'

Please see Appendix 3 for all responses.

Question 7: If your child has been discharged were you given any information about where you could get support from in the future?



31 responses received.

Question 8: What recommendations would you make to improve the CAMHS service?

Themes coming from responses to this question:

- More staff
- Shorter waiting times
- Better support pre-diagnosis – advice on where to get support, including whilst on waiting list
- Better support post-discharge, including easier way for re-referral
- Emergency appointments for those in crisis
- Earlier intervention
- Groups for the patients and the families
- Where else to get support from – outside organisations
- Help for longer than a course of treatment – i.e. don't discharge just because finished 6 sessions
- Don't just communicate by phone – use email

- Earlier diagnosis
- Family support – including for siblings
- Money - more investment in the services
- Better support for those who struggle to engage – use of alternative contact methods/Skype/Facetime etc.
- Listen to parents
- Lower staff turnover

Please see Appendix 4 for all the responses to this question.

Question 9 Any other comments

Comments included:

- As a parent at the beginning of this quite daunting time understanding what lies ahead for our son, it would be good to access support for us and for someone to be able to explain who all the different services are and how it all fits together. It's hard enough without feeling totally confused as to who does what. The only people who have actually offered any practical support are nursery - everyone else just writes a report and disappears
- There is a huge shortage of children's mental health services in York, particularly for anxiety and attachment issues. Cut backs are not what's needed at Limetrees- children are our future generation and it's important to be able to offer the help needed in a decent time frame
- I think an emergency access point should be that. Not 2 weeks later. Even a weekly drop in session would be helpful
- Trying to book appointments is extremely difficult as the doctors seem to run their own diary. Recently when an appointment was cancelled I wasn't given an alternative nor was I contacted with a new appointment. I had to contact them then wait two days before they phoned with an appointment at which point my daughter was suffering from some side effects from the medication
Also some transcripts had been mislaid resulting in a letter to my daughters GP being delayed this resulted in my chasing them up as my daughters meds were running out and the GP was being asked to prescribe them now

- Since we started seeing Limetrees two weeks ago there is already an improvement and I no longer feel alone in this. The support is amazing it's just a shame it takes so long to be seen. More funding please City of York Council
- The staff are lovely but everything seems to take a long time and it's frustrating to always have to chase things up
- There does not seem to be sign posting from health visitors g.ps not all doctors are on the same page re diagnosis even hospital seem to have limited resources for parents awaiting diagnosis. The process takes far too long leaving families in dire situations without support
- There doesn't seem to be another level of support once you have exhausted all the usual techniques
- Difficult to get hold of by phone and don't let you know where you are in the process
- The people we have seen have been very lovely & have helped as much as they were able but when we needed help we couldn't get it. I dread the next time my child needs help quickly - he is getting older & has more ideas on how to "leave this life" so quicker response times are imperative
- Siblings need support. To avoid siblings becoming CAMHS user too this needs to be addressed and information given to those young people about services that can access themselves for support
- Help the children sooner
- Biggest and worse area of all the services we use
- Our child got a diagnosis and is currently awaiting further assessment as of yet Limetrees haven't returned my call regarding how long waiting time are expected to be for his next few assessments
- There seems to be only one option when it comes to mental health for children and it's a struggle to get help

Please see Appendix 5 for all responses to this question.

Conclusion

Despite the increasing attention on Child and Adolescent Mental Health Services both nationally and locally, and commitments from the Department of Health, NHS trusts and local CCGs, the results of this survey suggest that there are ongoing and deep rooted issues with access to and support from this service. Although the results only capture a small number of families accessing or waiting to access CAMHS, it gives insight into their experiences. It provides useful information about how these families would like CAMHS to develop in the future.

It appears that there are long waiting times, both for assessment and diagnosis. A number of organisations and individuals have expressed concern about the acceptability of the 6 month to 3 year wait that vulnerable children may experience, with 85% of those who took the survey saying that earlier help would have made a difference. However, there was the general theme that once in the system, the support offered by CAMHS in York was generally beneficial. The survey results do suggest that increasing the length of support CAMHS provide to children and their families would be helpful, and that more staff would also be advantageous.

There were comments that support in schools could be improved, and that earlier diagnosis would enable better understanding of how both schools and families could best support the child.

Throughout the survey, there were comments about there being a lack of information about where else families can go to get support, both whilst waiting for an assessment or diagnosis from CAMHS, or post-discharge. Lack of support for parents and families was also a concern raised by the survey respondents, including specific issues regarding siblings.

The process of getting carers support via a carers assessment was also raised as a concern. In order to get access a carer assessment, the child needs to have been identified as disabled, and therefore needs a diagnosis. This means those waiting for support and diagnosis from CAMHS are unable to access a carers assessment and therefore unable to get the support that they need.

It must be noted that these results differ from the CAMHS Friends and Family Test of April to October 2017, which reported that over 80% of

those who access CAMHS would recommend it. However, the findings from our survey are in common with the understanding of the issues set out by the update on mental health performance, presented in the Vale of York CCG Governing Body Meeting in September 2017. This suggests that when looking at the experiences of those using CAMHS services in the future, it would be useful to work alongside CAMHS and other organisations to reach more individuals and get a better and wider understanding of the views of those accessing CAMHS.

Overall, the responses to the survey suggest that more work needs to be done to improve access to and support from local CAMHS in the York area, to ensure that this service is best supporting the children and young people of York and their families. Below, we set out our recommendations that we believe are needed to make improvements in this area.

Recommendations

Recommendation	Recommended to
Consider further investment in Early Intervention & Prevention Services to help reduce waiting times for CAMHS	NHS Vale of York CCG (VoYCCG) City of York Council (CYC) Tees Esk & Wear Valleys NHS Foundation Trust (TEWV)
Consider ways to provide faster emergency appointments for those in crisis	TEWV / VoYCCG
Consider long-term treatment options for young people who return to services to maintain mental wellbeing and prevent crises	TEWV VoYCCG
Develop different ways of communicating with families for appointments and assessment – e.g. through email rather than just telephone	TEWV
Improve support for those who struggle to engage, including offering more appointments in a format that the child/young person is most comfortable with, such as Skype or Facetime appointments, or at a venue that they feel 'safe', to enable them to best engage with CAMHS	TEWV VoY CCG
Clearer pathway for children/young people and/or families to re-engage with services post discharge	TEWV
Consider ways to support improved communication with other bodies that provide services such as voluntary and private sector services	VoYCCG, TEWV, York CVS, CYC
Consider how to strengthen signposting to other services that can provide support/help to children/young people and their families, including better signposting to voluntary sector/peer support such as York Carers Centre, York Parent Carers Forum, York Inspirational Kids (see Appendix 2)	TEWV VoYCCG City of York Council (CYC)
Work effectively with schools & families and improve support for schools to ensure that all children experiencing emotional and mental health difficulties receive the best support possible at school	TEWV; VoYCCG; CYC

<p>Improve access to appropriate Carers Assessment of needs and support for parent carers, including for those who are waiting for a CAMHS assessment, diagnosis or further support</p>	<p>CYC; TEWV; VoYCCG</p>
<p>Consider ways of improving support for siblings, including proactive identification and signposting of young carers</p>	<p>TEWV CYC VoYCCG</p>

Initial Response from Tees Esk and Wear Valleys NHS Trust (TEWV) and NHS Vale of York Clinical Commissioning Group (VoY CCG)

Both VoY CCG and TEWV were keen to highlight that the results of this survey are based on a small number of individuals accessing or waiting to access CAMHS services, and were gathered in a small time frame. TEWV said: “We absolutely take the concerns raised in this paper seriously, and work to ensure all families get the service that they deserve, i.e. timely access to an evidence based outcome-led service. However, it is important to recognise the sample size of families accessing CAMHS that these views represent”.

VoY CCG said that “we agree that it’s important to have the figures in context of the size of the caseload at CAMHS (currently 1921) and the responses for the Friends and Family test, (the most recent done between July and October 2017 indicated that 88.9% would be extremely likely or likely to recommend the service to friends and family if they need similar care or treatment). However we also agree that if families have poor experience, then the issues need to be flagged to ensure there are no systemic problems”.

They were also keen to highlight that many changes have already been or are currently being implemented to improve CAMHS services, and they should make a significant difference to some of the issues raised in this report.

Actions that have already been taken to implement the 5 Local Transformation Plan priorities:

- Priority: Promotion, prevention and early intervention:
 - Action: The introduction of well-being workers in schools
- Priority: Easier access to support:
 - Action: The introduction of the Single Point of Access (SPA) into CAMHS services

TEWV and VoY CCG have given their initial responses and comments to specific issues raised in the report as follows:

Concern with waiting times:

- The current figures for August 2017 suggest that 84.62% were seen for their second contact with the service within 9 weeks of referral. The current contract target is that 90% are seen within this time frame, but this is a large improvement from the average of 66% between September 2016 and April 2017

- Susan De Val from the Vale of York CCG commented that “this represents good progress in managing the waiting list, and represents the effects of the SPA and latterly the effect of the crisis team in reducing calls on clinician’s time”
“The evidence is that waiting times are reducing, although the CCG is undertaking very close monitoring of the position to better understand the full waiting time to start treatment. With the reductions in waiting times for assessment it appears at present that the investment in the mental health contract in 2015 is having an effect”
“We know from current monitoring data that very few are now waiting over 10 weeks for assessment and the CCG is waiting for details of average waits from referral to treatment to complete the picture of the journey through CAMHS”
- Despite the results in Question 2 which asked ‘If you are awaiting a diagnosis how long ago was your referral’, TEWV said that there are currently no waiting lists that are three years for specialist neurodevelopmental diagnosis. Additionally, the amount of time a clinician will wait before making a diagnosis for certain conditions different from other conditions, in order to allow a child to develop further, so the reports of long delays before getting a diagnosis can be misleading.
- In terms of the waiting times for an initial assessment, the implementation of the SPA has led TEWV to set a target of contacting families within one week of referral for a 30 minute telephone consultation, with a turnaround target of 24 hours. Data from August 2017 shows that 95.15% have had a telephone consultation in the first 4 weeks of being referred, showing an improvement from the 22% of those waiting for an assessment or treatment with CAMHS in York who were waiting longer than 12 weeks.⁶

Responses to other concerns raised in the report:

- Increasing the number of staff in CAMHS requires increased funding, however the recent capacity and demand analysis provided by TEWV is to be discussed
- Waiting times are expected to improve following changes such as the introduction of SPA
- Emergency appointments: Since September 2017, the CAMHS crisis team operates from 10am to 10pm 7 days a week to support

⁶ NHS Vale of York Clinical Commissioning Group Quality and Patient Experience Report, July 2017

those in crisis, and provide emergency appointments as appropriate

- It was highlighted that there are specific groups for service users and family/carers. However TEWV and the CCG take on board that the development of a support group would be welcomed by service users and their families/carers
- In response to the call for support for longer than just a course of treatment, it was confirmed that this was a matter of clinical judgement. Around 50% of the current CAMHS caseload has been with CAMHS for over 6 months. Additionally, considering long-term treatment options for young people to maintain mental wellbeing and prevent crisis would reduce capacity for new assessments and access to the service. This would be difficult to achieve without further investment in services
- The suggestion for communication to service users and their families/carers to be done via more than just telephone was welcomed, but it was pointed out that the reason this hasn't been employed is probably due to the current IT infrastructure
- Possibility of the development of a "What to expect in CAMHS" leaflet to be sent out with all new initial assessment appointments
- The current service specification requires high quality detailed information on signposting and support. There was suggestion of CAMHS working with Healthwatch York to develop a leaflet detailing local services that can support parents/carers and young people, which could be given to individuals alongside their initial assessment appointments and discharge
- The current service specification requires detailed communications with families, as identified co-ordinator for families, and this should be upheld in all instances
- Families can now re-refer themselves via SPA if they feel they need to
- CAMHS said they would be happy to engage in a joint initiative regarding improving communication between other bodies that provide services such as voluntary and private sector organisations
- In response to the recommendation regarding working effectively with schools and families, it was pointed out that CAMHS currently offer supervision and consultation to well-being workers located within schools, and school professionals can access the clinicians working on SPA for consultation regarding a young person. However, it was noted that there was a need to understand that schools have primary legal responsibility for the emotional and

mental well-being of pupils, and in York there is strong support for initiatives to improve, including workforce development, and additional public health funding for school mental health mentors

- Improving access to appropriate Carers Assessment of needs and support for parent carers was welcomed. There was comment on developing a leaflet for parents/carers with other national and local parent/carer support information regarding this

Both TEWV and VoY CCG were supportive of repeating the study in a year's time to see the difference these changes are making to the experiences of those trying to or accessing CAMHS. They were appreciative of the information it has given them in highlighting areas that still need to be looked at, and appreciated the honesty of those who took the time to answer the survey.

Appendices

Appendix 1 –. Newspaper Articles

<http://www.cypnow.co.uk/cyp/news/2004025/government-to-recruit-2-000-additional-camhs-staff>

http://www.yorkpress.co.uk/news/15078226.York_MP_speaks_out_on_child_mental_health_waiting_lists/

Appendix 2 – Sources of Support For Children and Young People:

Ambition

www.ambitionuk.org/

Ambition is the leading youth charity, reaching half a million young people every year across the UK inspiring and encouraging them to achieve, improving health and wellbeing by developing confidence, life skills and resilience.

ATLAS

01904 464680

york@lifeline.org.uk

York's Young People's Drug and Alcohol Service. ATLAS can help anyone under the age of 25 who wants to talk about drugs and alcohol. Can provide 1:1 support anywhere in the community to make sure you get the help and support you need.

B-eat

0845 634 7650 (Monday to Friday evenings from 4.30pm to 8.30pm and
Saturdays 1.00pm - 4.30pm)

fyp@b-eat.co.uk

www.b-eat.co.uk

Information, help and support for anyone affected by eating disorders.

Childline

0800 1111

www.childline.org.uk

ChildLine is a private and confidential service for children and young people up to the age of nineteen. You can contact a ChildLine counsellor about anything - no +problem is too big or too small including advice, information and help on a range of emotional health issues.

Call free on 0800 1111, have a 1-2-1 chat online or send an email through the website.

Childline app Zipit

www.childline.org.uk/info-advice/bullying-abuse-safety/online-mobilesafety/sexting/zipit-app

An app created by Childline to provide young people with advice for sexting and top tips for staying safe whilst texting/chatting online.

Includes a function to call Childline.

Childnet International

www.childnet.com

Work in partnership with others around the world to help make the internet a great and safe place for children. Also work directly with children and young people from the ages of 3 to 18 on a weekly basis, as well as parents, carers, teachers and professionals, finding out about their real experiences online and the positive things they are doing as well as sharing safety advice.

Also practical advice and teaching activities to help teaching staff explore e-safety with young people with autistic spectrum disorders in Key Stage 3 and 4. Plus information on staying safe online for parents, young people and teachers.

The Children's Legal Centre

www.lawstuff.org.uk

The Children's Legal Centre is a charity that promotes children's rights and gives legal advice and representation to children and young people.

The Cybersmile Foundation

www.cybersmile.org

Tackling on-line bullying and hate campaigns. Providing support, help and advice for young people, parents/carers and professionals. Email and twitter service to ask questions plus helpline services.

Caremonkeys

www.caremonkeys.co.uk/

Web-based app providing information for young people on issues such as sexting and bullying. Links to websites such as Childline for reporting and "safe zone" button to keep searching confidential.

HeadMeds

www.headmeds.org.uk

Straight talk on mental health medication. Look up your medication to find out about side effects and things you might not feel comfortable asking your GP about and listen to other people's experiences.

MindFul

www.mindful.org

MindFul provides 11-17 year olds with tailored support to improve their wellbeing and mental health. By helping them to improve their emotional resilience and develop positive coping mechanisms, MindFul equips young people with the tools and emotional foundations needed to fulfil their potential.

The Mix

Freephone: [0808 808 4994](tel:08088084994)

www.themix.org.uk

An online guide to life for 16 to 25 year-olds.

It provides non-judgmental support and information on everything from sex and exam stress to debt and drugs.

Mood Juice

www.Moodjuice.scot.nhs.uk

Self-help resources on issues such as anxiety, depression and bereavement. Also information for parents/carers and professionals.

Anger? Panic? Assertiveness? Anxiety? Stress? Chronic Pain? Bereavement? Phobias? Depression? Post-Traumatic Stress? Obsessions and Compulsions? Sleep Problems? Shyness? Addiction? Carers Support? Feel in Crisis?

Emotional problems often indicate that something needs to be changed in our life. Mood Juice helps you think about emotional problems and work towards solving them.

Stem4

www.stem4.org.uk

A charity aimed at improving teenage mental health by stemming commonly occurring mental health issues at an early stage. Covering eating disorders, self-harm, depression and anxiety, and addiction. For young people affected by the conditions, their friends, their families and carers, schools – teachers and nurses

Talk to Frank

0300 123 6600

www.talktofrank.com

Friendly, confidential advice on drugs. Chat facility, phone line. Live chat, email, phone and text service. If you want to talk, you can call FRANK, **24 hours a day, 365 days a year. Online chat 2pm-6pm any day of the year.**

Need a quick answer? Text 82111 a question and FRANK will text you back.

Young Carers Revolution

<https://www.yorkcarerscentre.co.uk/young-carers/young-carers-revolution/>

Blog: www.ycryorkuk.wordpress.com

01904 715490

Young Carers Revolution (YCR) provides empowerment and influence to young carers and young adult carers (8 to 25 years) in York. Its purpose is to proactively influence services provided for them by statutory and third sector organisations. Although administered by York Carers Centre the group has its own autonomy and sets its own agenda for projects and campaign themes.

YCR is open to all young carers and young adult carers living in York. It is run by a team of volunteers and supported by York Carers Centre.

The office is open Monday to Thursday 9am to 5pm and Friday 9am to 4.30pm. The telephone lines will be open 9.30 to 4.30 Monday to Friday for information and guidance.

Young People's Project (York Mind)

Highcliffe House Highcliffe Court,
York YO30 6BP

01904 643364

vicky.blakey@yorkmind.org.uk or

rab.ferguson@yorkmind.org.uk

www.yorkmind.org.uk

Providing support for young people between 13 and 25 who are recovering from mental health issues. The mentoring service provides 1-to-1 support where people, over a 12 week period, build their confidence by setting their own goals. The Arts Award project is available for people who are aged 13 to 16 and 16 to 25. The project will support individuals to explore a range of creative arts activities.

Young People's Survival Guide

www.yorksurvivalguide.co.uk

The Young People's Survival Guide to York is a useful little book full of things you might need to know or make decisions about. It also has places you might need to contact for help and advice. It is written for young people 16-25 in York (though you might find it useful at any age). The guide is produced by the friendly people at Castlegate.

Do you want to talk to someone face to face? There are places you can go to in York especially for you.

29 Castlegate, York YO1 9RN

01904 555400

mail@29castlegate.org

www.29castlegate.org

Offers information, support, advice, guidance and counselling to young people aged 16 to 25 who live in York. This includes practical and emotional support, advice on sexual health, benefits, debt, housing options and housing rights and help with employment, training and education.

Appointments: Monday to Friday, 9am to 5pm.

Drop in: Monday to Friday, 11am to 4.30pm.

YoungMinds

www.youngminds.org.uk

The UK's leading charity committed to improving the emotional wellbeing and mental health of children and young people with information and advice for young people, parents, carers and training for professionals.

The YoungMinds Parents' Helpline: **0808 802 5544 is free for mobiles and landlines and open from 9.30 to 4.00pm, Mon- Fri.**

For general enquiries:

yemenquiries@youngminds.org.uk.

We'll try to get back to you within 48 hours.

Write: Suite 11, Baden Place, Crosby Row, London SE1 1YW

Youth Access

www.youthaccess.org.uk

A national membership organisation for youth information, advice and counselling agencies. Provides information on youth agencies to children aged 11-25 and their carers but does not provide direct advice.

For Parents and Families

MindEd

www.minded.org.uk/

MindEd is suitable for all adults working with or caring for infants, children or teenagers; all the information provided is quality assured by experts, useful and easy to understand. We aim to give adults who care for or work with young people the knowledge to support their wellbeing, the understanding to identify a child at risk of a mental health condition and the confidence to act on their concern and, if needed, signpost to services that can help

York Carers Centre

17 Priory Street, York YO1 6ET

01904 715490

enquiries@yorkcarerscentre.co.uk

www.yorkcarerscentre.co.uk

York Carers Centre helps unpaid carers in York find the support they need. They have services for young carers (aged 8-18), young adult carers (18-25) and adult carers. They support carers regarding their individual situations, and can provide this over the phone, at the office, at home or another suitable place.

Offering carers:

A Carers Emergency Card

Discounts at businesses in York

Free, regular newsletters

Social activities for carers

Employment, education & training support

Help filling in forms

The opportunity to have their voice heard by decision makers

A dedicated advice worker

Information and advice service

The Carers' Mental Health Group runs in partnership with carers themselves, York

Carers' Centre and Rethink York branch.

Meeting monthly on the 2nd Wednesday of each month, alternating between a carers informal sharing /peer support session and discussion group.

York Carers Forum

yorkcarersforum@tiscali.co.uk

www.yorkcarersforum.org

York Carers Forum supports and empowers unpaid carers and former carers (aged over 18) by gathering information for carers and sending it out in a free monthly newsletter and e-newsletter: "York Carers Voice".

Drop-in meetings, speakers and events, provide respite such as mini massages or trips out.

York Inspirational Kids

01904 780880

info@keyworking.co.uk

www.keyworking.co.uk/

York Inspirational Kids is for parents of a child with disabilities/additional needs in the York area. They aim to provide information and support to all our members along with family and parent events.

York Mind Carers Peer Support Group

Darrin at York Mind: 01904 643364

darrin.thomson@yorkmind.org.uk

Meets regularly to promote the well-being of carers for people with mental health issues.

York Parent Carer Forum

15 Priory Street, York, North Yorkshire, YO1 6ET

info@yorkparentcarerforum.org.uk

07751828369

York Parent Carer Forum are a parent/carer forum for children and young people aged 0-25 with disability or additional need who access services in York. They aim to represent the views of families of children and young people who have physical and Sensory impairments, learning difficulties and those who have been identified with additional needs.

Appendix 3 – Comments from Question 6 in response to the question: Q5. If you had been able to get earlier help would this have made a difference?

- We still have no idea what our child's condition is and have had to go through 3 years of school so far using trial and error approaches. Knowing what the condition is would help in understanding how to deal with it appropriately
- Asked for help from age 4 via primary care MH workers. Eventual referral into CAMHS age 11. No formal ASC diagnosis until age 15. Earlier help would have helped increase support at school
- I find it is very hard to get referred and seen by lime trees
- She has had no support since leaving our previous LA in Oct 2015
- Referred by GP to Lime Trees but they don't give any support until he is 5
- If earlier diagnosis had happened, support from other agencies and school would have been put in place when really needed. Instead my child's needs increased through anxiety of school not knowing what to do, no support for us as a family and we hit crisis point before getting screening and diagnosis
- Anxiety is the problem with my son. We did get an appointment after the GP and the doctors had sent many letters. We were told we would get support for Anxiety 3 months ago and still waiting. I do wonder if we have been forgotten. Quick email to keep us informed would be lovely
- It would have stopped the prolonged anxiety that both my children experience
- Still waiting to be seen and struggle at home and school
- Awaiting an autism diagnosis and my son is deteriorating and has started self harming, school lack understanding and will not help until he has a diagnosis so just punish him when he can't cope treating him like a naughty child. If his diagnosis had happened earlier help would be in place for him both in and out of school
- Just helping my child to understand his emotions might have prevented him from self harming
- Allow recognition of needs; provide evidence of needs
Allow access to ascend and other elements only available to those with diagnosis
- Would have been nice to have the support

- It might have stopped things from reaching crisis point and stopped my child from self harming
- would have avoided stress and breakdown of relationships in family
- My son suffered emotional needs and was discriminated against during his primary school years because the school didn't understand his needs and were unable to support him as he didn't have a diagnosis at the time. This made it difficult for myself and my husband to work and I had to pay extra to support him myself on school trips and residential visits
- There would of been more help earlier and strategies in place so he was able to do well instead he was slipping further away from his education and lost confidence
- First referral from GP dismissed in June 2014. Then referred again in 2015 by paediatrician put on long waiting list and fobbed off for a long time after getting MP involved saw someone in July 2016 who did back us and pushed for autism assessment diagnosis finally given in December 2016 and only now starting to get the correct help in school and we are getting more support. This could have happened a lot sooner and maybe helped us all a lot sooner
- The wait for support is so long and you're on your own just muddling through
- We we're discharged last year and then had to go almost straight back on the waiting list again. We then had to wait 7 months to be seen during which time our child had to make the transition from primary to secondary school
- Could have put support in place whilst at junior school
- I went to Limetrees and I told them my son had ADHD when he was 10 they wouldn't listen to me just fobbed me off for 2 yrs then they finally decided he had ADHD ... but we had struggled with his behaviour and he had got himself in trouble with the police if the Limetrees doctors had listened to me at first , and put him on Medication he would not have been so bad . And his school work has suffered because he couldn't concentrate and sit long enough to listen and learn
- My child was suffering with anxiety, including suicidal thoughts ... we waited 5 months for an initial meeting, then another 3 months before we were allocated a therapist ... I fear that this delay has caused irreparable harm to his confidence & mental health

- Early intervention would have helped manage anxieties with both son and rest of family but due to the long waiting times and having to keep 're referring through school/GP the difficulties have become in manage and resulted in crisis for whole family therefore both parents and siblings mental health deteriorated resulting in support from mental health for all at crisis level and marriage breakdown
 - 'X' has been failed been under this for 5 years nearly 6 no diagnosis as yet had to go to Selby
 - We didn't know what to do for him how to help where we making it worse he's got worse and worse escalating all the time gone from been anxious to self harming and having bad thoughts no other service can help until diagnosis school didn't want to know
-

Appendix 4 - Comments from Question 8: What recommendations would you make to improve the CAMHS service?

- Whilst I haven't had any direct dealings yet I am fearful of the reports I hear of an overwhelmed and confused service. I am really hoping our experience doesn't match the reputation
- More staff! Waiting lists are ridiculous and the new SPA system isn't working very well at the moment. Staffing levels have been cut and it's only causing more anxiety and stress for parents which is adding to the problems the children have. Other professionals can no longer make any difference to referral times and putting 'everything into one pot' is clogging up the system
- Interventions with schools whilst children are undergoing an assessment. Help for children during assessments
- Not to completely close files but to have a period of time when you can still go back for advice following discharge
- - Link more fully with other bodies e.g. council LAT; schools
- - Manage waiting lists better
- - Provide more ascend style courses
- - Allow drop-ins / support groups access to those pre-diagnosis
- Provide emergency appointments when crisis occurs e.g. self harm
- Recognise that school behaviour may be good and receive feedback from other bodies e.g. childminders, cubs, activity groups to allow evidence of behaviours to be seen more fully when many of our kids 'hold it together' at school leading to poor behaviour elsewhere
- Quicker assessments. Also more support after diagnosis
- Earlier help, more available interventions
- Need more staff and resources. Also permanent help. Feel like CAMHS just like to sign patients off as soon as possible
- More groups to help the patients and the families
- More interaction with outside organisations that may be able to offer support
- Bigger service allowing people to be seen quicker for as long as they need rather than issuing a 6 session guideline for all problems no matter how big and setting this out at the beginning which puts pressure on the child from the start to get 'fixed in 6 sessions'
- Have a proper waiting list where people take their turn. It is hard for all of us, not just those that constantly complain
- To recognise and have support for PDA and OD

- Shorter waiting times. This is children we're dealing with, they shouldn't be left to suffer so long
- Try not to use Locums. More observation of child at home and school
- Shorter waiting lists for diagnosis
- Perhaps an easier way of communicating rather than just phone as it's difficult to get to speak to people so maybe email
- More money invested and more staff, enabling better service and support
- Prioritise the child's needs on the waiting list. Children in crisis should be top. Make medication changes available through the GP so appointments with CAHMS aren't always needed
- - Diagnosis earlier
- - Better support for siblings
- - More training in schools for teachers
- - More courses
- Look at each referral properly and individually - all children are different and have different needs. Time scales for help are ridiculous - children and families are suffering in the meantime
- More staff, more investment, just more of everything. Life is hard enough without waiting for support
- Shorter waiting times
- - Shorter wait time
- - Members of staff turnover too high.
- - A willingness to pass on if it is out of expertise
- - Improve ways of contacting specialists
- - Actually meet the children you are advising on
- - Discharging people when they have helped not because they have completed a set period of help
- Split autism spectrum assessments into fast track for low level needs and more depth where needs are higher, to speed up process where only basic diagnosis is needed. Also please standardize questionnaires between York and Tees systems
- More staff, quicker assessments, help that covers all of the major mental health areas - e.g. Attachment
- Ensure parents/young people have support of who they can access while in waiting list
- Ensure parents/young person have tools to maintain mental health at home to reduce re-referral and crisis
- Have better pathways for referrals back to the service. Many conditions don't go away after CAMHS support and need re-visiting

Look at support to help those most vulnerable that struggle to engage due to condition and not just discharge as min engager

- Listen to the parents
 - Length of waiting time actually getting past the mental health workers a joke [X] member of staff is useless - fobbed off, parents blamed. Actually listen to parents, meet with us without child, too many false promises, nothing put in writing, no plan, can't wait to discharge, you're a number not a person, too quick to judge, second guess, pass the book, no joined up working
 - Realise that not every child is going to fit in specific boxes. Listen more to parents and teachers, we know the children better than someone who has never met them
 - - Shorter waiting lists
 - Better communication with parents, read between the lines as parents forget the long list of things in which their child differs
 - Stop telling parents to not label when the whole outside world expects a label before you can access anything
 - Right strategies can only be put in place when right diagnosis gets made
 - Lower turnover in staff
 - Listen to the parents and not to the school the child is at
 - Read the information sent in from other sources (family friends/sports centres). Actually bother to read the file instead of lying to people
 - Quicker times for diagnosis and more support
-

Appendix 5 - Comments from Question 9: Any other comments

- As a parent at the beginning of this quite daunting time understanding what lies ahead for our son, it would be good to access support for us and for someone to be able to explain who all the different services are and how it all fits together. It's hard enough without feeling totally confused as to who does what. The only people who have actually offered any practical support are nursery - everyone else just writes a report and disappears
- There is a huge shortage of children's mental health services in York, particularly for anxiety and attachment issues. Cut backs are not what's needed at Limetrees- children are our future generation and it's important to be able to offer the help needed in a decent time frame
- I think an emergency access point should be that. Not 2 weeks later. Even a weekly drop in session would be helpful
- Trying to book appointments is extremely difficult as the doctors seem to run their own diary. Recently when an appointment was cancelled I wasn't given an alternative nor was I contacted with a new appointment. I had to contact them then wait two days before there phoned with an appointment at which point my daughter was suffering from some side effects from the medication. Also some transcripts had been mislaid resulting in a letter to my daughters GP being delayed this resulted in my chasing them up as my daughters meds were running out and the GP was being asked to prescribe them now
- Have Skype appointments for children that get anxious going to new places
- Since we started seeing Limetrees two weeks ago there is already an improvement and I no longer feel alone in this. The support is amazing it's just a shame it takes so long to be seen. More funding please City of York Council
- The staff are lovely but everything seems to take a long time and it's frustrating to always have to chase things up
- There does not seem to be sign posting from health visitors, GPs. Not all doctors are on the same page re diagnosis - even hospital seem to have limited resources for parents awaiting diagnosis. The process takes far too long leaving families in dire situations without support
- There doesn't seem to be another level of support once you have exhausted all the usual techniques
- Difficult to get hold of by phone and don't let you know where you are in the process

- The people we have seen have been very lovely & have helped as much as they were able but when we needed help we couldn't get it. I dread the next time my child needs help quickly - he is getting older & has more ideas on how to "leave this life" so quicker response times are imperative
 - Siblings need support. To avoid siblings becoming CAMHS user too this needs to be addressed and information given to those young people about services that can access themselves for support
 - Help the children sooner. 'X' year 6 September and no support at all but there thought she had ADHD aspect since 2014 but still no help
 - Biggest and worse area of all the services we use
 - Our child got a diagnosis and is currently awaiting further assessment as of yet Limetrees haven't returned my call regarding how long waiting time are expected to be for his next few assessments
 - Now been told to start again with GP, meanwhile things have escalated but when you ring to discharge you don't even check that families are ok and not in crisis. I told them things were worse now than ever only to be told nothing I can do I'm just passing on a message re discharge go back to GP
 - There seems to be only one option when it comes to mental health for children and it's a struggle to get help
-

Contact us:

- Post: Freepost RTEG-BLES-RRYJ
Healthwatch York
15 Priory Street
York YO1 6ET
- Phone: 01904 621133
- Mobile: 07779 597361 – use this if you would like to leave us a text or voicemail message
- E mail: healthwatch@yorkcvs.org.uk
- Twitter: @healthwatchyork
- Facebook: Like us on Facebook
- Web: www.healthwatchyork.co.uk
-

York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York. York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

This report is available to download from the Healthwatch York website: www.healthwatchyork.co.uk

Paper copies are available from the Healthwatch York office
If you would like this report in any other format, please contact the Healthwatch York office